Growing Together: Navigating the Life Stage Checklist for Families

Hosted by:

- Angelman Syndrome Foundation
- DEE-P Connections
- Pediatric Epilepsy Surgery Alliance
- Rare Epilepsy Network

Highlighted resources:

- Adulthood Transitions | REN
- C.A.R.E. binder: The C.A.R.E. Binder (Caring for Adults with a Rare Epilepsy) is a step-by-step guide to help parents and caregivers navigate the transition to adulthood for individuals with complex epilepsies. Developed in collaboration with leading rare epilepsy organizations, this detailed resource provides practical guidance to help families prepare for each stage of adulthood. VIPrareCARE.com was made possible through UCB funding and partnership to support families like yours.
- The Council of Parent Attorneys and Advocates (COPAA) is a national nonprofit that empowers families to advocate for their children's educational rights under laws like IDEA and ADA. For families of children with severe epilepsy transitioning to adulthood, COPAA provides essential resources and legal support to ensure schools address medical needs, cognitive challenges, and necessary accommodations for postsecondary education, employment, and independent living.
- Elevatus Training provides evidence-based, trauma-informed education on sexuality for individuals with intellectual and developmental disabilities, including autism. For families of children with severe epilepsy transitioning to adulthood, their resources help address critical topics like healthy relationships, boundaries, consent, and personal safety, ensuring young adults receive the guidance they need to navigate adulthood with confidence and autonomy.
- National Care Advisors specializes in creating comprehensive life care plans for individuals with complex medical needs, ensuring long-term sustainability, access to benefits, and quality of life. For families of children with severe epilepsy transitioning to adulthood, they provide critical support in navigating medical care, financial planning, benefits coordination, and future care needs, helping families secure a stable and well-supported future.

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Key resources from the Pediatric Epilepsy Surgery Alliance:

- Educational Transition After Epilepsy Surgery and Educational Transition For Youth With Neurological Conditions: These comprehensive guides help parents of children with neurological conditions use their "Individual Education Plans" (IEPs) to support the transition process. It also includes information about health transition, college resources, template letters, and checklists.
- Transition Roadmap for Youth with Neurological Condition: This self-paced companion course includes over ten hours of training modules covering all aspects of transition. In this series, you will find the steps you need to take to build your child's education transition plan, the transition to adult healthcare, future planning, decision-making, and financial support, among other topics.
- Navigating the IEP Process: This step-by-step course will walk you through creating an Individualized Education Plan.
- Special Education Resource Guide: A comprehensive spreadsheet designed for parents, caregivers, and educators; includes accommodations, related services, staff training, and more.
- The (Almost) Everything List: Our resource list includes information about school, adult life, financial assistance, decision-making, family resources, and more.
- Our website and YouTube channel offer comprehensive, valuable resources for families at any stage of their child's epilepsy surgery journey.
- Transition to Adulthood/Life Stage Checklist (Pediatric Epilepsy Surgery Alliance)

Healthcare transition

For families:

- Center for Transition to Adult Health Care for Youth with Disabilities (resources for young adults, parents/caregivers, and clinicians)
- A guide to health care transition after pediatric epilepsy surgery (Pediatric Epilepsy Surgery Alliance)
- Supporting Students with Epilepsy: A Transition Toolkit for School Nurses | NASN Learning Center (National Association of School Nurses, 2023)
- Young Adults with Rare Disease: YARR Healthcare Guide (EveryLife Foundation for Rare Diseases)

For clinicians:

- AES Clinical Practice Tools includes two nice planning guides:

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    - Adolescent without significant developmental disability (plan for independence)
    - Adolescent with significant developmental disability (independence unlikely)
- American Academy of Pediatrics:
    - Care Coordination & Health Care Transition for Youth/Young Adults with Epilepsy and Their Families
    - Epilepsy Resources for Health Care Professionals: Health Care Transition
    - Supporting the health care transition from adolescence to adulthood in the medical home (2018)
- Child Neurology Foundation Transition of Care
- PolicyLab Evidence to Action brief: Transitioning To Adult Care: Supporting Youth With Special Health Care Needs. Caren Steinway, Jennifer Gable, Sophia Jan
- Six Core Elements of Health Care Transition (Got Transition)
- Epilepsy Transition Readiness Assessment Questionnaire (EPITRAQ)[1] and Transition Readiness Assessment Questionnaire (TRAQ) [2] [3]

Citations:

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Goselink RJM, Olsson I, Malmgren K, Reilly C. Transition to adult care in epilepsy: A systematic review. Seizure. 2022 Oct;101:52-59. doi: 10.1016/j.seizure.2022.07.006.

[1] Clark SJ, Beimer NJ, Gebremariam A, Fletcher LL, Patel AD, Carbone L, Guyot JA, Joshi SM. Validation of EpiTRAQ, a transition readiness assessment tool for adolescents and young adults with epilepsy. Epilepsia Open. 2020 Aug 12;5(3):487-495. doi: 10.1002/epi4.12427. PMID: 32913956; PMCID: PMC7469762.
[2] Sawicki GS, Lukens-Bull K, Yin X, Demars N, Huang I, Livingood W, Reiss J, Wood D. Measuring the Transition Readiness of Youth with Special Healthcare Needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire, *Journal of Pediatric Psychology*, Volume 36, Issue 2, March 2011, Pages 160–171, https://doi.org/10.1093/jpepsy/jsp128
[3] Johnson K, McBee M, Reiss J, Livingood W, Wood D. TRAQ Changes: Improving the Measurement of Transition Readiness by the Transition Readiness Assessment Questionnaire. J Pediatr Nurs. 2021 Jul-Aug;59:188-195. doi: 10.1016/j.pedn.2021.04.019. Epub 2021 May 18. PMID: 34020387.

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